

2021 ANNUAL REPORT Arizona
Developmental
Disabilities
Planning Council

# Introduction

The Arizona Developmental Disabilities Planning Council (ADDPC) serves Arizona residents with intellectual and developmental disabilities (I/DD), along with their families, providing original research, education, advocacy, and financial support to disability-serving organizations that encourages Arizonans with I/DD to advocate for themselves and create more inclusive communities.

The Council's charge is to develop and support change to increase the involvement of people with developmental disabilities in their communities by:

- · Encouraging them to speak up for themselves
- · Increasing their choices
- · Helping them increase self-respect in all aspects of life

The Council receives funding from the federal government to do this work. Along with other responsibilities, Council Members vote to determine which projects can use these funds to improve the lives of Arizonans with I/DD.

In 2021, the Council focused on three primary goal areas: Self-Advocacy, Employment, and Inclusion. Council-supported projects contributed to significant progress this year. On the following pages, we are pleased to share some of the activities undertaken and accomplishments realized during 2021.

# **Self-Advocacy**

Self-advocates deserve the opportunity to speak up and be heard about why they need to make decisions for themselves, live self-determined lives where their choices are respected, and be valued and protected from all forms of neglect, abuse, and exploitation. ADDPC activities under the Self-Advocacy goal during 2021 supported the Council's commitment to ensuring that individuals with disabilities are afforded an equitable role in shaping their lives.

Furthermore, activities focused on self-advocacy and self-determination will continue to be central to our efforts in years to come, as these issues are of fundamental importance to the Council and the I/DD community.

### **Self-Advocacy Grant Activities:**

**Arizona Peer and Family Coalition (AZPFC):** The Council renewed its funding to the Arizona Peer and Family Coalition to expand the availability of the Civic Leadership Development (CLD) training to persons with I/DD throughout the state, and most specifically to those receiving services from the behavioral health system.

Through CLD, participants learned how to share their personal stories, identify issues that need reform, and strategize to impact change. This coalition was led by individuals with lived experience.

In Year 2, new training components were developed that allowed students to advance their self-advocacy skills and practice what they learned. The training also provided self-advocates with a greater understanding of how committees that work with disability organizations and/or state agencies operate, the rules individuals must follow to participate, basic attendance requirements, proper attire, and other necessary information to promote their success.

These courses provided an overview of advocacy and a teaser for the full CLD training and could be presented at local conferences and organizational lunch-and-learn meetings. A Spanish-language version was offered, as well, and was promoted to the Youth Build/AmeriCorps program in Yuma County and the local Promotoras. Two additional instruction pieces were also offered (a 60-minute Mini-training and a 90-minute Mini-training).

During 2021, 140 individuals received guidance in one of the five CLD training components -127 self-advocates and 13 professional stakeholders. Seven training sessions were conducted -2 of them in Spanish - along with the development of online training and a presentation of the CLD Minitraining to the  $53^{\rm rd}$  Annual Southwestern School for Behavioral Health Studies (SWS) Conference. The major activity of the SWS is a five-day conference held annually in Tucson, Arizona. This conference features nationally known speakers and local presenters addressing a wide range of topics relevant to behavioral health, child welfare, and addiction. Three of the CLD graduates now sit on the Olmstead Review Planning Committee of the Arizona Health Care Cost Containment System (AHCCCS) and 62% shared they have joined a community-based coalition or policy board.

**Transition AHEAD Roundtable (TAR):** The University of Arizona-Sonoran University Center for Excellence in Developmental Disabilities (Sonoran UCEDD) received funding to replicate a best practice model developed by the UCEDD at the University of South Dakota, the Transition AHEAD Roundtable, or TAR. Designed for up to six young adults with I/DD, ages 14-22, going to school in Tucson, the TAR project partnered with families, youth with disabilities, educators, and professionals

in the state to support the development, implementation, evaluation, and dissemination of a sustainable, innovative transition clinic designed to improve post-school outcomes related to employment, health, and independent living.

As approved for a second year, the Sonoran UCEDD will expand the TAR program in 2022 to 20 transition-age youth in more areas of the state, focusing on youth with I/DD in the foster care system, Native American and Hispanic youth, and those who have hearing impairments.

Additional information can be found at <a href="https://sonoranucedd.fcm.arizona.edu/programs-services/youth-adult-transition/transition-ahead-roundtable">https://sonoranucedd.fcm.arizona.edu/programs-services/youth-adult-transition/transition-ahead-roundtable</a>.



## Impressions of the Transition AHEAD Roundtable:

Family and professional participants...

- "I liked how everyone was on the same page with us as a family and people who wanted to listen and help my son on his next step."
- "This round table was great. I went in with no expectations and was pleased with all aspects of the discussion."

# Youth perspectives...

- "Everyone listened to what I had to say, and the conversations were very helpful."
- "The round table went very well. They got one-on-one and had me actively included."

**ADDPC Facilitating Change in Arizona:** Council grants made a significant contribution to the work of self-advocates across Arizona, expanding opportunities for self-advocates to have substantive conversations with government officials and give meaningful input on, among other things:

- Adult Protective Services training;
- COVID-19 vaccination sites, accessibility, and outreach;
- The Request To Speak system at the Arizona Legislature;
- Disability policy planning and implementation; and
- School emergency response

Several other organizations worked with ADDPC to devise more inclusive policies to better serve people with disabilities. Notable among these is an agreement by Yellow Cab Company to clarify with drivers that persons with disabilities are not to be charged lift fees, as well as the implementation of a state protocol supported by the Arizona Coalition to End Sexual & Domestic Violence (ACESDV) that includes guidance on how crisis shelters can be fully accessible when providing services.

The Council met with the Arizona Department of Education and Arizona Department of Health Services to share findings of a published report, No One Left Behind: School Emergency Planning & Students Who Have Disabilities, on the need to include students with disabilities in school emergency planning efforts. The meeting resulted in a commitment by the state agencies to involve students in the planning process.

# **Self-Advocate Highlights and Updates**

**Ability360 Vaccine Event**: In Spring 2021, ADDPC, self-advocates, Arizona Developmental Disabilities Network partners, and other disability organizations hosted a COVID-19 vaccination event for individuals with disabilities and their caregivers at the Ability360 Sports & Fitness Center in Phoenix. Following several education/training meetings with the Arizona Department of Health Services, vaccine providers, and Thunderbird Charities representatives to ensure the development of accessible event information and vaccine distribution methods, the event was held over the weekend of April 10-11. In those two days, 1,687 individuals with disabilities and their family members received first or second doses of a COVID-19 vaccine. (A follow-up clinic held the next month saw a remarkable 94% return rate for those needing second doses after the first event.)



### **Updates From Past Projects**

**School Participatory Budgeting (SPB) Project:** In 2020, the Council awarded School Participatory Budgeting (SPB) funds to the Center for the Future of Arizona at Arizona State University. SPB is a program by which schools, school districts, and colleges around the world are using student participation in the budgeting process to engage students, parents, educators, and staff in deciding how to spend a part of the school budget. During the second year of funding in 2021, the project continued at Carson Middle School, and school personnel and project staff refined and improved the model to increase the impact of inclusive school participatory budgeting. The project also empowered 19 special education students by offering mentoring roles, ensuring they are part of the steering committee, and giving them more opportunities to present and facilitate discussions.

A further project enhancement during this past year was to bring SPB to two high schools in Tucson's Sunnyside Unified School District, Desert View High School, and Sunnyside High School, where approximately 1,000 students, including students with disabilities, were engaged throughout the entire SPB process. Based on these experiences, they could publish a toolkit for inclusive practices in SPB. This toolkit is now freely available online.

In addition, because of the uniqueness of the project, how it is tied to civic engagement and rolled out in school settings to promote maximum student engagement, the ASU staff that participated in the project presented the toolkit to a group of 40 educators at the Professional Development Workshop for Educators hosted virtually in June 2021. This 3-hour workshop introduced

participating educators to the SPB model in Arizona schools. Ten other presentations on SPB were conducted in 2021 by the Center for the Future of Arizona at ASU, including at the American Educational Research Association (AERA) Annual Conference, the Arizona Department of Education 8th Annual Civic Learning Conference, the International Social Pedagogy Conference, and the UNESCO Chair International Symposium on Education, Citizenship, and Democracy.

**Self-Advocate Solutions (SAS):** Grant funding was originally awarded in 2020 to Southwest Institute for Families and Children with Special Needs (SWI) to coordinate development of a statewide network of self-advocacy organizations. The Arc of Arizona, a collaborator on this grant, hosted a virtual Self-Advocacy and Disability Conference on September 25, 2021. Ninety-five participants joined the conference online, which included 12 breakout sessions on a variety of self-advocacy issues and programs such as adaptive recreation, community employment, civic engagement, voting, supported decision-making, healthy relationships, and sex education.

The conference launched with a keynote speaker who discussed the history of the self-advocacy movement and a panel of self-advocates who spoke about their advocacy and self-determination efforts. It concluded with a presentation from self-advocacy groups currently enrolled in the funded project. The conference was recorded and is placed online on SWI's website (<a href="https://swifamilies.org/sas/saconference/">https://swifamilies.org/sas/saconference/</a>).

Native American Disability Law Center (NADLC) Equal Native Youth Voices: This program is centered on self-advocacy, employment, and community inclusion for Navajo-Native American youth with I/DD, as other sub-topics are embedded in the curriculum. The project's curriculum is rooted in Diné (Navajo) philosophy. In Spring 2021, 15 students participated, with 13 of them attending the final session on April 18 and completing the participant survey developed by NADLC.

The final session focused on presentations by 23 students and staff. These presentations offered an opportunity to demonstrate self-advocacy skills, including speaking for themselves and telling attendees about their academic and personal goals after high school. In addition, some students referred to the transition services provided by the Navajo and State of Arizona VR Services for technical training (all are Native American). Evaluation data collected at the end of the project showed students experienced an overall increase in their confidence in talking about their disabilities, knowing their rights and responsibilities, and taking part in decisions that affect their lives.

Although originally designed to be in-person, the project was moved online (via Zoom) due to COVID-19 restrictions at the students' school. This presented various challenges such as ensuring internet connectivity for all the participants — an amenity not universally available in some Native communities — but surprisingly this turn of events gave the students more confidence in voicing their thoughts about their employment and life planning goals after they graduate.

# **Employment**

During 2021, projects related to the Council's Employment goal advanced systems change to help individuals with developmental disabilities obtain and retain competitive integrated employment, participate in inclusive education, and attend college.

The Council's capacity-building work around Employment First has led to increased awareness and support for competitive integrated employment, while its public policy work is building momentum behind an effort to establish a state Office of Employment First. Much work remains to be done, but 2021 represented an important step forward in these areas. As a demonstration of this, the University of Arizona-Sonoran UCEDD's Job Coach Training project addressed the need for training employment support professionals through a series of training sessions focused on knowledge gains, resource sharing, problem-solving, and intensive skill development related to implementation of supported and customized employment services. Four hundred sixty-two individuals who provide employment supports and services received training to help improve employment outcomes.

### **Employment Activities:**

The City of Tempe's Building Employment Supports & Training (BEST) Pilot Program completed the final year of its three-year grant to sustain an integrated employment program for people with I/DD. The BEST program focused on three goals:

- Change the City of Tempe's inclusion culture and language competency;
- Hire six employees with developmental disabilities to increase neurodiversity: and
- Create a municipality model to share with others for replication.

The BEST Program published its replication toolkit for other municipalities on the City of Tempe's website for widespread availability, for program staff to update info, and to enhance accessibility for people with disabilities. The BEST Program distributed the final Culture of Inclusion survey to City of Tempe staff, the results of which indicated that 35% of staff had an increased comfort level with people with disabilities due to the BEST-related initiatives, and 53% of staff who attended at least one training experienced an increase in comfort level with disabilities. The BEST Program was featured as a model employment best practice in a national monthly Community of Practice webinar sponsored by the Disability Employment Technical Assistance Center (DETAC) during National Disability Employment Awareness Month in October. By program's end, BEST had hired five employees out of the goal of six.

"I have been a job coach with Focus Employment Services for approximately

five and half years and both times that I have worked with the BEST program it has been a pleasant experience...The BEST program has been wonderful in offering those with disabilities the opportunity to explore and maintain careers." - Job Coach, Focus Employment Services

# Project participation by ADDPC staff in 2021

**Third Thursday at 3, Apprenticeship Information Sessions:** ADDPC participated in monthly meetings facilitated by the Employer Engagement Administration and promoted Arizona@Work employment events and activities through the Council's social media. The 12 sessions provided a forum for employers to share information on their organizations, apprenticeship and hiring opportunities, and tips on applying. Attendees were employers, employment service providers, agencies, educators, transition specialists, and individuals seeking employment.

**Transform Arizona 2021:** The Arizona Chapter of the Association of People Supporting Employment First (AZ APSE), in partnership with ADDPC, hosted Transform Arizona 2021, a series of nine educational webinars to provide awareness and education about strategies used to promote best practices and positive outcomes through competitive integrated employment.

The educational webinars were created especially for employment service providers, job seekers, employers, VR and DD professionals, and family members of individuals with disabilities. More than 165 attendees benefitted from the webinar series. Two ADDPC staff members are active members of AZ APSE and participated in the presentations. The Arizona APSE Chapter, which was created with the assistance of ADDPC, has grown to 47 members. Eight of the APSE members have obtained a Certified Employment Support Professional (CESP) credential.

"As we look back over the 2021 year, despite all the changes and reconsiderations that have had to be made due to the pandemic, AZ APSE prevailed! Not only have we highlighted successful employment outcomes for people who have disabilities throughout the year, but it is also important to celebrate our increased AZ APSE membership, all the hard work our subcommittee members have done to develop and deliver a monthly webinar series addressing Employment First topical areas, the creation of an AZ APSE website, and the increased visibility through our communications efforts. Our AZ APSE members also participated in several activities during National Disability Employment Awareness Month in October and conducted a successful AZ APSE Annual Meeting with rich session presentations by local and national APSE presenters."—Susan Voirol, AZ APSE President

National Disability Employment Awareness Month: The 2021 theme was "America's Recovery: Powered by Inclusion" and included a Governor's Proclamation encouraging all Arizonans to recognize the strengths that people who have disabilities can bring to our workforce, our communities, and our state. Ten personal employment videos were created, each a story that included five self-advocates. Resources also were created to boost employment for people with disabilities. These resources were featured on the Arizona Employment First website.

# **Inclusion**

The goal area of Inclusion was intended to address the many other areas in which we recognized gaps in service over the past year. Topics included researching the Adult Protective Service (APS) system on how well it responds to calls about neglect, abuse, sexual violence, and exploitation against persons with I/DD and what sort of supports and services are provided to someone with I/DD who is involved in the criminal justice system.

The subject of protecting individuals with disabilities from abuse, neglect, or exploitation received even greater attention from the Council in 2021. It became very clear in every survey or focus group with persons with I/DD, and/or their families/caregivers and the agencies that support them, that current and ongoing information and training are crucial. Agency staff need training on best or promising practices they can implement — such as proper identification of a vulnerable person who has become victimized or how updated policies and procedures are central to protecting and providing trauma-informed care for that person. In addition, for this one objective alone, with the multiple activities that support it, a collaborative team has been put in place to look at each part of the system, ways to strengthen it, and where training and other resources are needed, including potential legislative changes.

Families frequently tell the Council that they need information, they don't know where to turn, or are frustrated with the agencies that are supposed to help them. They recount how various systems don't address their concerns and they feel their child will fall through the cracks. The Council's Inclusion work addresses these concerns by assembling stakeholders from across the state, representing individuals as well as public and private agencies, to conduct work that treats every person with an I/DD with respect and dignity, ensures their lives matter, and includes them in all facets of life, across the age span.

#### **Inclusion Activities:**

**Cultural & Linguistic Competency (CLC):** To better serve the growing number of refugee and immigrant residents in Arizona, the CLC leadership team this year undertook a significant number of activities to ensure that non-English-speaking communities can receive, and access linguistically accessible material related to services for individuals with disabilities, including in languages such as Dari, Swahili, Kinyarwanda, and Spanish.

The CLC leadership team met six times and began discussions with state agency leadership to address gaps identified in the prior reporting year. The CLC group also worked with a refugee stakeholder group to hold training for refugee resettlement agencies on disability and language rights and how to access disability services.

In addition, the CLC leadership group created an assessment tool that non-English speaking families can use to identify an appropriate provider. This assessment was translated into six different languages (Kinyarwanda, Spanish, Dari, Swahili, Burmese, and Arabic) and shared with refugee resettlement agencies. The CLC group also attended training led by Georgetown University's National Center for Cultural Competence and developed a plan to implement the information received. Working with a refugee stakeholder group, CLC leaders held training for refugee resettlement agencies on disability and language rights and how to access disability services; 46 individuals attended. The virtual training, conducted by the Arizona Center for Disability Law, was offered in five different languages and pointed participants to resources already created by the team, including six FAQ documents on special education requirements in the U.S.

### The DD Safety Coalition and the Criminal Justice & Self Advocacy Vetting & Planning Work

**Group:** The Council participated in and helped facilitate these two groups as part of its overarching work to respond to and/or prevent abuse, neglect, and exploitation of persons with disabilities. Between the two groups, a total of eight meetings were held, and each meeting had approximately 20 people in attendance. In the Criminal Justice group, the participants worked to develop a self-advocate resource guide with information on how to be in healthy relationships and to collaborate with Adult Protective Services to create a plain language flyer accessible to everyone. The flyer included information on the Council's latest report on abuse and neglect suffered by the disability community. The group also went through a similar process with the Division of Developmental Disabilities, with the goal of expanding the array of information available to help community members identify and report abuse or neglect when they suspect it is occurring.

Among other activities, the DD Safety Coalition created a survey that was distributed to police departments to assess the degree to which law enforcement officers receive training regarding interaction with individuals with disabilities and handling reported cases of abuse and neglect. The Council has played a significant role in various task forces and committees formed several years ago following the Hacienda HealthCare incident, in which a woman with an intellectual disability residing in a care facility was sexually assaulted by her caregiver, resulting in pregnancy.

**Arizona Sexual Violence & I/DD Response Collaborative:** The Arizona Sexual Violence & I/DD Response Collaborative is a coalition of stakeholders dedicated to spreading awareness and leading prevention efforts for sexual violence against people with I/DD across the state.

Drawing from its other collaborations, the Council remained committed to building upon research findings and recommendations about abuse and neglect to improve Arizona's system so an incident

like Hacienda never happens again. In July 2021, funding was awarded to The Arc of the United States, The Arc's National Center on Criminal Justice & Disability (NCCJD), and The Arc of Arizona to establish and guide a statewide, stakeholder-led effort to formalize, strengthen, coordinate, and expand previous work to include more representation from self-advocates; members of the legal, law enforcement, and criminal justice communities; individuals from underserved/underrepresented communities, especially communities of color and those historically marginalized; and healthcare professionals.

NCCJD is working closely with Collaborative members to create a strategic plan and core principles that define the group's overall work and create measurable outcomes to evaluate its progress. Four work groups have been formed — Training & Prevention for Professionals, School Abuse Prevention, Trauma-Informed Care Access, and Criminal Justice & Vulnerable Adults — and NCCJD will provide support and technical assistance to each of these.

Council staff remain actively engaged with NCCJD and the Collaborative to gauge their progress and provide any necessary ongoing support. As an element of its participation, the Council assisted in creating resources such as a <u>Training Directory</u> and a <u>Self-Advocate Resource Guide</u> focusing on healthy relationships and sexual advocacy.

Community Indicators Project (Data Hub): Determined to provide usable data that inform the work of researchers and disability professionals across the state, ADDPC funded the creation of the Community Indicator Project, or Data Hub, housing current U.S. Census Bureau data for Arizona's 15 counties. And because free and easy access to data on individuals with disabilities is important to develop and support capacity building and systemic change, the Data Hub — which will continue to be maintained and updated with current census data and in time will include information from a more diverse collection of sources — allows researchers, grant writers, public officials, or anyone else to see where each county stands in certain core indicators. The Data Hub is now live on the Council's website, offering the opportunity to explore data on individuals with disabilities living in the state of Arizona in six areas: Demographics, Employment, Housing, Income, Transportation, and Education.

# **Council Funded Trainings**

The Council provided funding in 2021 to five organizations that implemented virtual trainings for the I/DD community and stakeholders. Grantees included:

- Arizona Coalition to End Sexual and Domestic Violence, which provided three eight-hour workshops about the impact of sexual and domestic violence in the I/DD community;
- The Arc of Arizona, hosting its sixth annual Autism and I/DD Resource Conference;
- Southern Arizona Association for the Visually Impaired held an integrated employment-themed conference, titled, "Cultivating a Culture of Strength";
- Southwest Autism Research and Resource Center conducted two one-hour Inclusive

- Practices for Community Settings webinars for community members interested in learning about best practices in inclusion;
- Niagara University, which presented a comprehensive disability awareness training program for first responders; and
- Association for Supportive Childcare, host of its 30th Annual Celebrate the Young Child Conference.

Training materials were provided in plain language, and each grantee captured significant feedback from participants to inform the planning of future trainings and the pursuit of system improvements for individuals with disabilities.

## **Updates From Past Projects**

**Adaptive Recreation:** ADDPC funded a second-year collaboration with Northern Arizona Adaptive Sports Association (NAASA) and the Institute for Human Development (IHD) at Northern Arizona University to continue their adaptive ski program for persons with I/DD, which proved successful during its first year.

The program is based at the Snow Bowl Ski Area in Flagstaff, where skiing experiences are offered to individuals with disabilities using specially designed equipment. Travel stipends were made available to offset the costs for those traveling from Phoenix or farther to get to Flagstaff. NAASA also planned on certifying five additional ski instructors in adaptive skiing.

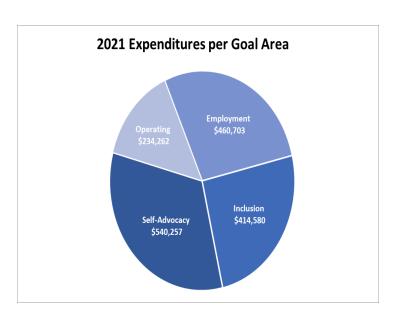
For the summer months, NAASA expanded the program for individuals with I/DD to experience adaptive kayaking and hiking. The team researched the feasibility of adding these two sports over the summer and identified safe and accessible locations throughout Arizona. NAASA also ensured that its staff were certified in Wilderness First Responder training, CPR, and basic first aid.

A parent wrote, "AZ Adaptive Sports Association has meant so much to our family in the short time we participated. Our son Ethan has cerebral palsy, low muscle tone, left-side weakness, and other disabilities. He's been in therapy his whole life...we started ski lessons with NAASA in the 2020 ski season at no cost to us, thanks to NAASA's funders ADDPC, and Ethan loved it! It has been the first sport that he's been excited to do again. He felt so good being able to go fast when keeping up with other typical kids has been a struggle. It has reminded us of Ethan's untapped potential. We would not have even considered some of these sports without the help of NAASA."

# **Agency Funding**

In 2021, ADDPC spent \$1,649,802 in federal funding to support programs and operations.

\$ 234,262
General Operations
\$ 460,703
Employment
\$ 414,580
Inclusion
\$ 540,257
Self-Advocacy



# **2021 Council Members**

### **MELISSA VAN HOOK**

Chair & Family Member

#### J.J. RICO

Vice-Chair, and Representative, Arizona Center for Disability Law (Protection and Advocacy System)

### **LAURA LUNA BELLUCCI**

Representative, Arizona Department of Health Services

#### **KIN CHUNG-COUNTS**

Family Member

#### **MICHAEL COEN**

Representative, Department of Economic Security-Division of Aging and Adult Services

### **MONICA COOPER**

Self-Advocate

#### **MEGHAN COX**

Family Member

#### **BIANCA DEMARA**

Family Member

### **VANESSA FELIX**

Self-Advocate

#### **ERIK JENSEN**

Self-Advocate

#### SCOTT LINDBLOOM

Self-Advocate

# JANNA MURRELL

Family Member

# **JAMES RIVERA**

Representative, Arizona Department of Education

### **MARY SLAUGHTER**

Family Member

#### **BENJAMIN R. KAUFFMAN**

Representative, Arizona **Health Care Cost Containment System** (AHCCCS)

#### **KRISTINA LOPEZ**

Self-Advocate

Provider Representative

#### **GABRIELA S. OROZCO**

# **WENDY PARENT-JOHNSON**

**KATHARINE** 

**LEVANDOWSKY** 

Family Member

**KRISTEN MACKEY** 

Representative. Department of Economic Security-Rehabilitation Services Administration

Representative, Sonoran University Center for Excellence in Developmental Disabilities-University of Arizona

#### **VIJETTE SAARI**

Family Member

# **MATEO TREETOP**

**KELLY ROBERTS** 

Representative, Institute for

**Human Development-**Northern Arizona (University Center for Excellence in **Developmental Disabilities**)

Self-Advocate

# 2021 Council Staff

#### Erica McFadden

**Executive Director** 

### Lani St. Cyr

Fiscal Manager

#### **Steven Freeman**

Communications Director

#### **Marcella Crane**

Contracts Manager

# **Jason Snead**

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#### Sarah Ruf

**Communications Director** 

### **Michael Leyva**

Contract/Grants Coordinator